Title: IUPUI Center for Cancer Population Analytics and Patient-Centered Informatics

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Abstract:

In 2012, 30,272 residents of Indiana were diagnosed with cancer. Cancer is the second leading cause of death in the state, claiming about 12,688 lives annually. $1.01 billion was spent in Indiana on direct costs of treating the cancer population in 2003.

Cancer care coordination has the potential to reduce costs and improve quality in cancer care delivery. Coordination may occur both among (1) multiple cancer care providers caring for populations of cancer patients, and (2) between providers and individual patients with cancer. Coordination of care goes to the heart of a central paradox of modern cancer care, namely, the potential for unparalleled quality is as high as ever, but patients are at risk of poorly coordinated care in a fragmented system. The *mission* of our research center is to develop team science that applies innovative health information technologies to create knowledge that will have an impact upon the health and health care of cancer patients and populations in the state of Indiana and the U.S.

To build our research portfolio, we have the following 2 main cores of activity:

I. Cancer Population Analytics Core: Created by the Regenstrief Institute, the Indiana Network for Patient Care (INPC) is the nation's most comprehensive and longest-running health information exchange. The Indianapolis area is the core of the INPC, and includes nine counties in central Indiana. The INPC repository receives data from approximately 8 million unique patients annually from over 200 data sources, including 80 emergency departments, 60 hospitals, and 100 clinics. INPC represents clinical "big data".

Data will be linked from INPC to both the Indiana state tumor registry and personal health record (PHR) platforms (II). The unique opportunity here is to use the rich, clinical data in the EHR to answer key clinical epidemiologic questions about cancer care delivery, and ultimately design interventions to improve cancer patients' lives.

II. Cancer Patient-Centered Informatics Core: OpenMRS is an open-source medical record system developed by the Regenstrief Institute. Building upon this platform, a personal health record (PHR) module has been developed and tested among patients with colorectal cancer (CRC). The PHR includes the following functions:

Tab	Functions
My History	Allows review of cancer diagnosis and treatment (surgery, chemotherapy, and radiotherapy)
My Plan of Care	Patient-directed decision support for follow-up tests, tailored based upon cancer type
Communities	Links to Web sites for cancer survivor support groups and patient educational information
My Mail	Client-based e-mail application to communicate with health care providers or caregivers
My Journal	Searchable electronic blog (journal) to collect personal observations from the patient
Relationships	Creates a set of role-based relationships and permissions to access all or part of the PHR
My Symptoms	Patients enter structured information about their symptoms and receive tailored feedback about how to self-manage symptoms

Product development of new versions of cancer PHRs will include the use of iterative design and usability methods. We will set out to test the value and impact of cancer PHRs using comparative study designs, including randomized controlled trials. The following types of outcomes will be assessed: process (adherence to guideline-concordant care), clinical (psychosocial and physiologic morbidity),

behavioral (patient self-efficacy), patient-centered (perceived quality of care and care continuity), and implementation (qualitative observations of the context of patient-provider coordination).

We aspire for IUPUI to become a national leader in using institutional and personal electronic health information to study and improve the quality of cancer care.